

Personally Speaking

All About People

Volume 1, Issue 5

DIVISION OF MENTAL RETARDATION SERVICES

January, 2005

Open Wide!

- PASS Grant Value
- Thank You Letter
- Happy Anniversary
- Art Touch

NOTE: Due to space constraints Up Close and Personal was excluded from this issue. It will return in March

PASS Grant Shows Its Value

Following is a letter sent to Michelle Taylor, Personal Assistance Supports and Services (PASS) Grant Project Director from Martin McGrath, a consumer. PASS is a federal grant awarded to the state by the Centers for Medicare and Medicaid Services. It involves Home and Community-based services with the objective to allow the recipient an avenue of care resulting in more independence.

Participating in the PASS program has indeed been the most rewarding experience that I've had in a long time and it couldn't have come at a better time, not once, but twice. Back in November of last year my uncle who is my sole caretaker, had to have cataract surgery. One of the conditions was that he couldn't do any lifting for a week. The other time was in August when Uncle Jim had to go into the hospital to get his medication straightened out. Both times I had a very caring, gentle and understanding Personal Assistant to tend to my needs.

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"Puttin' On the Ritz" *Knoxville's Prom of the Stars a Big Hit!*

Top hats and tails and elegant evening gowns! The third annual Prom of the Stars in Knoxville, a free event for physically and mentally challenged individuals, ages 15 and older, sported a large group of Beau Brummels and Lady

challenge," said Prom Coordinator Jim Riner. "They have the same desires as anyone else in our community and we should provide opportunities for them to participate in various activities. Why would you ignore such a large portion of the community in which you live?"

There was no shortage of support. Tuxedos for the guys and dresses for the girls, pictures, food, prizes and music were all donated by local businesses. Ladies had their hair,



Astors. Over 400 persons donned their finest and made a night of the gala, which is held on the first Saturday in November. The party was organized by the Farragut Christian Church.

"In Knox County, approximately 71,000 persons live with a physical or mental

makeup and nails done at the church just before the event. Individuals, families and various organizations volunteered their time. The

cont. page 5

From the Desk of Deputy Commissioner Stephen H. Norris

Happy New Year to everyone. I hope your holidays were enjoyable and restful.



Everyone I spoke with earlier I told to enjoy the time off and rest as 2006 will be a very busy year. There is much to be accomplished and I will touch on some priorities later in this column, but first I would like to reflect on the progress DMRS made in 2005 – progress as a result of an incredible effort by DMRS employees, providers, advocates and consumers.

Last year we bid farewell to the moratorium and welcomed new waivers. The DMRS plan “A Blueprint for Improving the Service Delivery System for Persons with Mental Retardation in Tennessee,” implemented in 2004, was successful.

The moratorium expired and the Centers for Medicare and Medicaid Services informed TennCare on April 14th that DMRS was free to begin enrolling persons into the waivers. DMRS had submitted renewal applications for its programs and a new one, the Self-Determination Waiver, which is directed to persons on the Waiting List who do not require residential services. With the expiration of the moratorium and CMS approval of the three waivers DMRS was moving forward.

The benefit and impact of Consumer-directed Supports was evident last year.

Funding for the supports began in July, 2004. The supports are for eligible persons on the DMRS Waiting List to purchase services, equipment or supplies not otherwise available through the Medicaid State Plan or other community resources that address an identified need. From its inception to last fall 1,320 persons were served and \$2,458, 839 spent. From July 1 to October 14th last year 951 persons were served and \$1,728, 217 spent.

A new comprehensive Quality Management System for Community Services was established. The system, with its Quality Assurance Assessment unit, has become a powerful vehicle for measuring the performance of providers and ensuring resolution of issues.

A provider oversight structure, titled “Agency Teams Initiative,” was implemented and has proven successful. The teams were created to support the annual quality assessment process, specifically to ensure follow-up to any deficiencies and to promote compliance between surveys.

In April the National Association of State Directors of Developmental Disabilities Services recognized the DMRS Quality Assurance unit for outstanding work.

During the past year current features of the Protection from Harm system were strengthened and several new ones added. The Complaint Resolution structure was modified to more effectively respond to persons needing assistance. Much emphasis has been placed on Incident Prevention.

cont. next page

PASS Grant...cont.

I’ve been a staunch advocate for attendant care for the past thirty years. Learned many, many years ago, that personal assistance (or the lack of) is crucial in attending college. I attended Peabody College (now part of Vanderbilt) for two years back in the early ‘70’s. Had to quit after the second year for not being able to find an attendant.

I’ve been extremely fortunate in belonging to a large and loving family. My father was one of six and my mother was one of nine. My mother passed away in 1964 when I was 14. My Dad died in 1973 when I was 23. When Mom died my Grandparents and three uncles, on my mother’s side, took me in. So for a long time my support system consisted of five people. But Ole Man Time has dwindled that down to one person. The PASS program has prevented, not once, but twice, a train wreck from happening. I can’t imagine living in a nursing home and shudder at the thought from reading and hearing the horror stories.

I always have heard that personal attendants are hard to come by. I had a flier put up at a grocery store a few blocks from me on a Saturday morning. Sunday evening a lady called. She came the next day for an interview, which was my first. After one other interview I hired Margo Weaver, a nurse from Scotland. I admit I’m not the easiest guy to care for with all my habits and quirks. With Margo’s extraordinary skills and patience it was a perfect match! I have said this many times that God connected us! After all who knows what I need better than He?

It is my hope that this day will be the day in which we officially start changing the culture of this state and country in how it cares for its seniors and people with disabilities. Instead of housing them like cattle like Floyd Stewart use to say, let them continue to thrive in an environment they’re most comfortable in, their homes! ■

Martin McGrath
Nashville, TN

DMRS Welcome Mat Still Out For Friends from New Orleans

On September 6th of last year 120 persons, 40 service recipients and 60 agency staff and family members, arrived at Clover Bottom Developmental Center following their escape from Hurricane Katrina. DMRS opened its doors wide and the center became home for agencies Crossroads of Louisiana and Hood Management Group.

The welcome issued by Clover Bottom Chief Officer Levi Harris, Middle Regional Director Cathleen Clinton and their staff was nothing short of remarkable. The foundation they laid, along with a generous outpouring of hospitality from the Nashville community has made for a very soft landing for our visitors. Following is an update on our friends' situation.

The Forty Clients of Crossroads and Hood

Thirty-seven clients remain at Clover Bottom; the other three returned to New Orleans. Clover Bottom continues to provide direct care staff on weekends, including some temporary employees hired specifically for that purpose.

Crossroads Staff and Families

By Thanksgiving, all staff and families had secured housing in local apartment complexes. Most took advantage of federal funds available through Mid Cumberland Community Services agency, which provided six month leases.

Several families and individuals were helped in furnishing their apartments through local churches which were contacted by Clover Bottom and regional office staff. Among the

participating churches: Donelson Heights United Methodist Church, Andrew Price United Methodist Church, Calvary United Methodist Church, First Baptist Church of Smyrna and Woodmont Hills Family of God. Other churches and families worked directly with the New Orleans families to provide various kinds of support, from housing to vehicles to cash.

Future

Over the next few months Crossroads and Hood Management will be locating housing and direct care staff in New Orleans. As needs are met arrangements will be made for their clients to return to the city. Clients will move in groups of one to six, and their specific New Orleans support staff with them presently will make the move as well. This process will continue until all the clients have returned to Louisiana.

Message

Clover Bottom Assistant Chief Officer for Administrative Services Don Wilson provided the information for this update. During the holidays Wilson forwarded an email to DMRS employees. It is worth sharing.

"Physical evidence of the things that happened here among us these last few months is already fading fast. The impact made on people – those who actually joined us, and the many others who worried for their loved ones' safety – is more permanent. In this season, I encourage you to take joy in the certain knowledge that all those extra things you did this year touched many lives for the good."

- Don Wilson, Clover Bottom Developmental Center ■

From the Desk of...cont.

Revised protocols streamlined the definitions for abuse, neglect and exploitation to bring DMRS in line with state statutes. In the first nine months of 2005, 39 persons were placed on the Abuse Registry, which is more than in the previous nine years combined! Protection from Harm also added a Director of Investigations and Director of Complaint Resolution.

For the first time in six years a DMRS provider resource was addressed. The DMRS Provider Manual was issued in March. The book was designed to capture all provider requirements in one document. The directives contained in the manual set the quality expectations for services for community providers. The manual will be updated annually.

Payment of services to providers was changed. With the help of providers a new rate structure was implemented based on the assessed needs of the individuals served, and the costs to provide the necessary level of support and service. The change was an effort to improve the quality of service and the provider's ability to deliver services in a cost-effective manner.

It was a busy year at the developmental centers. Safety is a main priority for persons with mental retardation and their families, when considering and evaluating residential services. To emphasize its importance each developmental center has implemented processes to assess each person to determine who may be at risk of injury. Appropriate program and managerial measures are put in place to assure that each individual is protected from harm.

Measuring devices were created to assure compliance with court orders. Each requirement is detailed through the application of over 1,000 questions each month in each center.

Greene Valley Developmental Center received accreditation by The Council on Quality and Leadership. This council is a nationally recognized authority on quality measures, performance measures and outcome achievement for persons with developmental disabilities.

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Louisiana Letter to Governor Bredeesen

From the Desk of...cont.

DMRS worked closely with the Direct Support Professional Association of Tennessee (DSPAT) in an effort to take the organization to another level. Successes were: The creation of a full-time DSPAT director's position, allocation of funds for DSP salaries, representation on the DMRS Advisory Council, implementation of recognition, mentoring and credentialing programs and the start-up of a bi-monthly newsletter. With these advances we are creating a better caliber workforce, which will elevate the quality of life for Tennesseans with mental retardation, as well as the DSP's.

The Division introduced a new newsletter, Personally Speaking. The bi-monthly publication, targeted to all stakeholders, features news and human interest stories, columns, announcements and advocate contributions.

The "From the Heart of Tennessee" program grew tremendously the past 12 months. The program addresses the potential and capabilities of the persons DMRS supports. Residents and the developmental centers produce a variety of products such as bird houses, greeting cards, dog treats and bath salts.

The residents fashion their products at adaptive work stations utilizing innovative and customized tools under the guidance of center staff. Their wares are sold at Tennessee State Parks and other businesses.

One accomplishment for which we should all be very proud is the response put forth for the two provider agencies from New Orleans, escaping Hurricane Katrina. Clover Bottom Developmental Center became home to 120 persons – 40 service recipients, 80 staff and their families and one dog. The acts of kindness and extraordinary effort to make the guests feel comfortable made by the Clover Bottom and DMRS Middle

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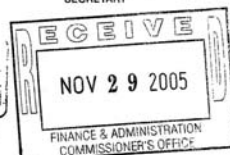
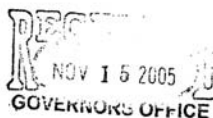


Kathleen Babineux Blanco
GOVERNOR

STATE OF LOUISIANA
DEPARTMENT OF HEALTH AND HOSPITALS



Frederick P. Cerise, M.D., M.P.H.
SECRETARY



November 7, 2005

The Honorable Phil Bredeesen
Governor
The State of Tennessee
The State Capitol - Governor's House
Nashville, TN 37243

RECEIVED DEC 01 2005

Dear Governor Bredeesen:

On behalf of the Office for Citizens with Developmental Disabilities (OCDD) and the people with developmental disabilities in Louisiana that evacuated due to Hurricane Katrina, I would like to share my sincere gratitude to you and the city of Nashville for your generosity in providing a continuous flow of shelter, food, clothing and medical care to those individuals affected by the recent disaster in our area.

Commissioner David Goetz, and Deputy Commissioner, Steve Norris immediately recognized the need for extended housing for a group of residents and staff of Crossroads Louisiana, Inc. and facilitated their transfer from Falls Creek Fall State Park to the Clover Bottom Developmental Center within days. In addition to the transfer, they immediately implemented support and services even prior to leaving the campgrounds.

Your Assistant Commissioner, Fred Hix, Assistant Deputy Commissioner, Dr. Larry Latham, and Regional Director, Kathleen Clinton, were also involved in the safe transfer. I am appreciative of their personal assistance and empathy.

Special thanks to the Dr. Harris and the Clover Bottom Developmental Center staff. I've been informed the entire staff, the doctors, nurses, directors, office personnel and custodians made our staff feel welcome and secure at the center.

Allow me the opportunity to thank you again, for the assistance that the people of Tennessee and you personally have provided to the State of Louisiana in our time of need. If you are ever in need of our assistance, please don't hesitate to contact my office at 225-342-0095.

Sincerely,

Kathy H. Kliebert
Assistant Secretary

CHK:eb

C: Peter J. Calamari, III
Gerald J. Murphy, Ph.D.

OFFICE FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES
1201 CAPITOL ACCESS ROAD • P.O. BOX 3117 • BATON ROUGE • LOUISIANA 70821-3117
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"AN EQUAL OPPORTUNITY EMPLOYER"

“Puttin’ On the Ritz” ...cont.

Farragut High School Swim and Dive Team assisted, and a Girl Scout contingent from Franklin joined in to learn how to put on a similar event next year.

“This year’s prom was a huge success,” said Riner. “Everyone –



the participants, volunteers and organizers – all have such a great time. The joy and gratification you feel is



beyond description. Our prom is growing each year and is becoming a major event in Knoxville.” ■



From the Desk of...cont.

Tennessee Regional Office staffs went far and above the call of duty.

Now, it is on to this year with a full agenda. DMRS is partnering with the Tennessee Housing Development Agency (THDA) in a very creative project to build 12, four-bed homes for service recipients. THDA provides the construction dollars and manages the construction process. Once complete, DMRS will use state-bonded dollars to replace the THDA expenditures. This will be an ongoing program with the homes this year placed in Shelby County and in subsequent years spread throughout the state.

A new DMRS Family Handbook will soon go to the printer. This is a guide for families, written in plain language that clearly outlines how to access Division services. The present handbook was distributed in 1998.

Major items on our agenda are simplifying our system, most noticeably Case Management and service authorization and delivery. We will work diligently to achieve full compliance with the provisions of the court orders and CMS requirements, and to bring services to persons eligible, but not yet receiving services.

Finally, a warm welcome to our new West Regional Director Cate Newbanks. Cate joined us in November and hit the ground running, restructuring and instituting new systems. She brings high expectations and already there is a bounce forward in the West.

Once again, Happy New Year to everyone. We must not rest on our laurels and approach 2006 with the same intensity and commitment we had last year. DMRS employees, in conjunction with our stakeholders, have proven time and again they are a cut above the norm. There is no doubt in my mind 2006 will be a very good year. My best to everyone. ■

Medical Message

Dr. Adadot Hayes, M.D., DMRS Medical Director

Building Successful Behaviors over the Last Decade

Dr. Hayes is having members of her staff pen columns for Personally Speaking. This message was written by State Behavior Analyst Coordinator George Zukotynski

A wise man once said, “No one walks in the same river twice.”

Behavior supports and behavior services in the state of Tennessee have been continuously changing over the last decade. Starting in 1995, the direction of these services has been influenced by the Department of Justice, the Center for Medicare and Medicaid, international behavioral consultants, and the changing leadership in the Central and Regional Offices. Over these years, the number of behavior analysts and behavior specialists in the Division of Mental Retardation Service system has grown from zero to over 350 professionals providing services in communities, regional offices and developmental centers. Throughout all the changes over these years, the focus of behavior services has remained the same: the design of individualized environments to promote socially successful behaviors for people who live in our Developmental Centers and in our communities. This article provides some background on applied behavior analysis, positive behavior supports, behavior services, and the professionals that provide these services.

Behavior is a way that we all communicate our needs, wants, and interests. These behaviors tell the world something about who we are : our personality and our motives. Our behaviors are sometimes quite revealing and at other times baffling. All of us have ideas about the people around us based upon our experience with their behaviors. However, some



*Dr. Adadot Hayes, M.D.
DMRS Medical Director*

professionals need to measure and study specific behaviors more precisely because these behaviors are impacting the person’s participation in life. Doctors and nurses, psychiatrists, psychologists, and therapists are all interested in specific behaviors and how they change as a result of their treatment.

A distinct professional group emerged in the late 1960’s which focused on behaviors, often helping to understand the behaviors of persons with developmental disabilities and mental retardation. They referred to themselves as behavior analysts and carried out applied behavior analysis.

Applied behavior analysis is the science of human behavior. Applied behavior analysis interventions are based upon the scientific principles of learning theory and are designed to improve important social behaviors. Applied behavior analysis relies on objective measurement and changes in observable behavior. Thousands of published research studies have documented the effectiveness of applied behavior analysis across a wide range of people, settings, and behaviors. Generally, the published studies focused on the intensive study of one or a few people, carefully measuring pre-intervention levels of behavior, applying an intervention in a consistent and reliable fashion, and measuring the observable behavior changes.

Applied behavior analysts are trained to analyze behavior through the use of a

functional assessment. Functional assessments are based upon observations and data collection in the settings where behaviors of interest are taking place. A functional assessment provides information on the purpose of the behavior and helps us to understand the physical and social contexts that predict the behavior.

The function of behaviors is interesting and can be useful in understanding why certain behaviors seem to be preferred. For instance, a person who enjoys the attention of others may find that in certain social environments, “acting out” is the most effective way to gain attention. If the social environment is shifted to encourage and respond to more socially appropriate behaviors, the person may rely on these appropriate behaviors because they are equally or even more effective than “acting out”.

In the mid 1990’s, some behavior analysts began to write about applied behavior analysis using the term positive behavior support or positive behavioral interventions. Positive behavior supports focuses on assisting the individual to gain socially adaptive behaviors and to decrease maladaptive behaviors. Selected interventions developed from studies on applied behavior analysis are used to teach functional skills as a replacement for problem behavior. Positive replacement behaviors that serve the same function as the problematic behavior are emphasized, along with adjusting the environment so that the opportunities for engaging in the inappropriate behavior are reduced. The behavior service model in Tennessee emphasizes positive behavior supports.

Applied behavior analysis studies have revealed how critical the social and physical environment is to the development of socially important behavior. The total environment needs to be considered. Thus, a well written Individual Support Plan, a quality residential and day service, good health services, and the consistency of positive reinforcement for the social behavior may all have an impact on positive behavior. The role of parents and direct support professionals who interact with the person each day is absolutely critical in

Medical Message...cont.

supporting positive behavior. The more sensitivity there is to attending to positive behaviors, the less likely negative behaviors may be needed to gain important effects. DMRS provides training on "Quality Behavior Supports," emphasizing the importance of direct support professionals and others in maintaining positive behavior support environments.

In some cases, behaviors that are dangerous, problematic, excessive, or unusual become barriers or risk factors impacting participation in the environments that are important to the individual. These behaviors are complex, but behavior providers may use a functional assessment to provide critical information and recommendations to direct support professionals and other members of the team about what to do. In some cases, these behaviors may be communicating a medical disorder, or a mental health disorder. In some cases, the behavior may relate to environmental learning and it will be necessary to prepare and to train a behavior support plan.

In Tennessee there are two types of behavior providers, DMRS Approved Behavior Analysts and DMRS Approved Behavior Specialists. DMRS Approved

Behavior Analysts are trained at the graduate level and write functional assessments and behavior support plans. DMRS Behavior Specialists are trained at the undergraduate level and assist the behavior analyst in training and monitoring the behavior plan. Since 2005, all new applicants for DMRS approval as a behavior provider must have or gain a license or certification within three years of approval.

Over the last ten years, there have been many success stories in the application of behavior services in the Developmental Centers and in the community. These stories have reached out to all types of people who have benefited from behavior change procedures.

The success stories are built around a partnership between the behavior provider

and other team members that produces an effective behavior support plan. An effective behavior support plan must consider information from a variety of sources, including information from the person, the direct support professional, the parents, and other providers, such as nurses, therapists, and psychiatrists. Understanding the roles of direct support professionals, parents, agencies, and other service providers are critical. Behavior support plans that are based upon stakeholder input and are written in clear language have been the most successful.

Behavior providers have worked successfully with psychiatrists, sharing important functional assessment information. Sometimes the behavior data reported to the psychiatrist has had an important impact on psychotropic medication recommendations made by the doctor.

Behavior providers have worked with other therapists, such as speech pathologists, in designing behavior change plans that have included functional communication. These plans have helped the individual to use a socially appropriate behavior to communicate his or her wishes, rather than a more negative and sometimes dangerous behavior.

Behavior providers have helped very complex people who have lived in the Developmental Centers or in the Mental Health Institutes to make a successful transition to the community. Behavior providers have helped individuals that were hurting themselves many times per hour (self-injurious behavior) to decrease these behaviors and to develop alternative behaviors to control their environment. Other individuals are now able to participate in work settings and to enjoy dinner in a restaurant.

The state of Tennessee continues to grow in the quality and sophistication of its service system. More and more behavior providers are becoming licensed or certified. The behavior support plan has evolved to be a more direct and clear document. The behavior providers continue to rely on a partnership between providers and director support professionals to be more successful.

Advanced techniques of functional assessment are revealing more clearly the function of a person's behavior and what the language of behavior is revealing. It is anticipated that the continued development of residential and day services will result in more positive behavior support environments. It is anticipated that applied behavior analysis techniques will help other professions, such as medical, psychological, and therapies to be more effective.

Over the last ten years, behavior providers have established a firm foundation for their services, and the quality of life for the persons they have served has improved. It will be interesting to see behavior services continue to evolve over the next decade. The river keeps on flowing and behavior services will continue to change. ■

"Touching" Exhibit Coming to Frist

Persons with visual impairments will have the opportunity to experience how the sense of touch can enrich their appreciation of art. ***Beyond Sight: African Art Touch Gallery***, will be on display at The Frist Center for the Visual Arts from January 27th through April 30th.

Normally, in order to protect artworks from damage, visitors are not permitted to touch paintings and sculptures in museums. For the purposes of this exhibition, eleven African art objects are provided so that persons can discover through touch the expressions and materials of the works as well as their forms, scales and textures.

For visitors who are blind or have low vision, each object is accompanied by information in Braille and large type. Persons should call **615-744-3247** at least three weeks in advance to schedule a tour.

The Frist Center for the Visual Arts
919 Broadway
Nashville, Tennessee

Happy Anniversary!

Rutherford County Adult Activity Center Celebrates 30 Years!

It all started in 1975 in the old, austere Chritchlow Gym in Murfreesboro. The Rutherford County Adult Activity Center was born with offices in closets, rats in the kitchen and employees sharing bathrooms with the public. Teamster leader Jimmy Hoffa disappeared that year, but current center director Betty McNeely swears he wasn't under the floor.



Rutherford County Adult Activity Center Executive Director Betty McNeely watches as sparks fly when the air conditioning is turned on in the original building (1981)

Over 200 persons, including service recipients, friends and families, helped the center celebrate its 30th anniversary recently. An awards banquet was the setting as a host of supporters and employees, past and present, were recognized. McNeely is a 27-year veteran – 23 years serving as director. When she started she planned on staying 12 months.

"Times do change," said McNeely. "We have come such a long way, growing and building our supports and services. We are very proud of what we have accomplished over the years and the programs that we provide now."



Rutherford County Adult Activity Center

"The center has been uniquely blessed by community and county support, great board members, the health care community, wonderful families and dedicated employees. Many of our staff has been with us for a very long time; throughout they have always been a team – a lot of caring, committed individuals."

Rutherford County Adult Activity Center began as an adult day care:



Original board members, L to R: Gerald Cohen and Thomas E. Batey.

Recreation, reading and writing being the staples. The county constructed a new building around 15 years ago, followed by an expansion courtesy of the Christy Houston Foundation.

A number of awards were issued at the banquet. Impressive was the Individual Achievement honor going to Donald Whorley. Whorley has worked more than 15 years at

Middle Tennessee Medical Center with near perfect attendance, saving enough money to purchase his own home.

The Spirit of the Center Award was given posthumously to Bruce Sanford. The award is presented to the person who best represented the center's values of bravery, thoughtfulness and good citizenship. Sanford, remembered as conscientious and always positive, served as the center's janitor and was a member of its human rights committee.

Rutherford County Adult Activity Center 30th Anniversary Celebration Awards

Distinguished Service

Thomas E. Batey
Horace Beasley
Gerald Cohen
W.H. Davidson
Percy Dempsey III
Robert Haston
Robert E. Rose

Friends and Family

Mel Adams
Shirley Cherry
Avent Dismukes
Ann McBride
Thelma and Jerry Mitchell

Public Service

John Mankin

Community Service

Dr. Frank Carter, MD
Dr. Walter Chitwood, DDS

F • R • I • E • N • D • S



People Talking to People Building Quality and Making Change Happen

In October 2003, the Department of Finance and Administration, Division of Mental Retardation Services (DMRS) was awarded one of the New Freedom Initiative Real Choice Systems Change Grants through the Centers for Medicare and Medicaid Services (CMS). This three-year grant, contracted to The Arc of Tennessee, will provide DMRS the opportunity to gather information in the form of Satisfaction Surveys conducted throughout Tennessee.

This innovative program creates the core of a system of quality assurance and quality improvement based on large numbers of consumers providing functional feedback. This feedback results in timely remediation and system-wide quality improvement. It accomplishes a paradigm shift, moving from a collection of overlapping and often redundant quality assurance activities to a system that is powered and led by the voices, priorities and choices of consumers and their families.

The feedback gathered during this three year period will allow for system-wide quality improvement by giving consumers and their family members a voice, thus able to control important choices and decisions in their own lives. PTP has also created a committee run by families and self advocates helping with the recommendation process.

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T E N N E S S E E
C O U N C I L



DEVELOPMENTAL DISABILITIES

Public Review of Council's New Five Year State Plan Sought

Alicia Cone, Ph.D.

The Tennessee Council on Developmental Disabilities has completed a comprehensive review of the Tennessee disability service system. A number of issues were identified that need to be addressed, in order to improve people's access to and the availability of consumer-driven, consumer-directed community-based services and supports.

Those identified needs were turned into the goals and objectives the Council will pursue over the next five years, beginning in August 2006. Since so many people were willing to provide Public Input into the plan, the Council is again asking for assistance in completing the State Plan, by entering into a period of time, from January 15th to February 28th to allow for Public Review. The Council would appreciate any feedback offered from Speaking Personally readers.

The Council is providing copies of the complete State Plan at the locations and on the web sites listed in the table below so that any member of the public who wishes to may review it and provide the Council with comments.

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T E N N E S S E E
D I S A B I L I T Y
C O A L I T I O N

Project B.R.A.I.N.

Project B.R.A.I.N. is a Brain Resource and Information Network for educators, families, and healthcare professionals who support Tennessee students with Traumatic Brain Injury (TBI).

The Tennessee Disability Coalition and the TBI Program established a partnership in July of 2000 with a shared goal of improving educational outcomes for students in Tennessee with traumatic brain injuries (TBI). TBI, as defined by the IDEA (Individuals with Disabilities Education Act), is "an acquired brain injury caused by an external physical force that results in a functional disability that adversely affects a child's educational performance."

With funding from the Health Resources and Services Administration's Maternal and Child Health Bureau and Tennessee's TBI program, Project BRAIN was developed to address the issues around identifying and supporting these students in school.

"Because the effects of TBI often resemble that of other disabilities such as

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a learning disability, Attention Deficit disorder, behavior disorder, or mild mental retardation, children with traumatic brain disorder are often misdiagnosed. Or, they may not be diagnosed at all. This, combined with the high but often unrecognized, number of children with traumatic brain disorder, gives rise to the disability's alternate name – the “silent epidemic.”

Vol.7 No.7 March 2001 www.cec.sped.org

Based on a successful “TBI Resource Team” model implemented in other states, Project BRAIN has established resource teams in selected school systems across the state. BRAIN Resource Teams are comprised of professionals from varying disciplines who have received extensive

training on educating students with TBI. Team Members act as consultants for the school systems in which they work, and may also provide basic training and resources to colleagues and families as needed.

TBI is the leading cause of disability and death among children in the United States. Despite the high incidence of traumatic brain injury among children and youth, it is still considered a “low incidence disability” within educational settings. In turn, there is often a lack of training and information made available to education professionals to prepare them for supporting students with TBI in educational settings.

Project BRAIN provides free “Brain Injury 101: Supporting Students in the

Classroom” training to school systems, families, health care professionals and related service providers around the state. The primary objective of “Brain Injury 101” is to help people who support students with TBI understand the nature of brain injury and the unique needs of this group of children and young adults.

Designed by experts in pediatric brain injury, this training session includes basic information about the following: brain injury; the potential impact of brain injury on physical, psychosocial, and cognitive skills; considerations for planning of educational services, including information about local and national resources.

The incidence and characteristics of TBI are given faces and names with the project video, “Take Two: After Traumatic Brain Injury”, a collection of interviews with Tennessee students who have sustained brain injuries, their families, and the professionals who work with them. Case studies further personalize the material by allowing participants to apply useful strategies to actual physical, cognitive, and social profiles of students with TBI. Participants are also given a copy of the PowerPoint® slides, educational handouts and articles, which continue to be a useful resource long after they attend “Brain Injury 101.”

In 2005, building on Project B.R.A.I.N.’s successful foundation, the program has developed a new training module entitled; “Partners in Communication.” This training is designed to assist healthcare professionals, families and school systems to identify TBI and share information on possible changes that may result from an injury. This “train the trainer” module will be presented to hospital emergency departments across Tennessee. Establishing effective and ongoing communication links between hospitals, homes and schools will help provide the opportunity for a students’ overall well-being.

For additional information about Project B.RAIN, visit our website @ www.tndisability.org/brain or contact Paula Denslow @ 615-383-9442, TTY 615-292-7790, via email: paula_d@tndisability.org. ■

TCDD ...cont.

Agency/Provider	Contact Information
Council on Developmental Disabilities, Nashville	Alicia Cone, 615-253-1105 The State Plan is also available on the Council’s web site. The address is www.state.tn.us/cdd .
Disability Law and Advocacy Center (formerly, Tennessee Protection and Advocacy, Inc.), Memphis Office	Andrea Johnson, 901-458-6013
Disability Law and Advocacy Center, Knoxville Office	Peggy DeVault, 865-689-9020, ext. 10
Boling Center for Developmental Disabilities, Memphis	Elizabeth Bishop, 901-448-3127 A copy of the State Plan will also be posted on the Boling Center web site. The link may be accessed at www.utmem.edu/bcdd . Please go to the Boling Center’s home page, and scroll down to the section titled Items of Special Interest.
University of Tennessee Center on Disability and Employment, Knoxville	Kim Rutherford, 865-974-9400
Vanderbilt Kennedy Outreach Center, Tennessee Disability Information and Referral Office	The plan will be available through a link from the Tennessee Disability Pathfinder web site. The web site can be accessed at www.familypathfinder.org .

Alternative formats will be made available upon request. Mailed copies are also available upon request. For an alternate format, a mailed copy, or

questions about the State Plan please contact Alicia Cone. alicia.cone@state.tn.us 615-253-1105. ■



Community Involvement Is the Path to Success

The Vanderbilt Kennedy Center is a national center for research on development and disabilities and a

The ARC...cont.

The Arc of Tennessee put together a group of 20 consumers and people familiar with disabilities (such as a family member) to work as interviewers across the state. People Talking to People Director Lisa Greenman has selected and trained teams of two to complete the Participant Experience Surveys with attention to detail and emphasis on respecting each consumer's right to privacy.

Currently there are two interview positions open (one in Davidson County and the other in Carroll County). Please call for more details.

The first round of surveys began in Davidson, Knox and Madison Counties. This year the selection sample will increase statewide. The second year was a great success and the PTP team is hard at work to reach the third year goals. If you would like to learn more about the PTP program or if you have questions or comments, contact Lisa Greenman, Project Director, at 615 248 5878 x 23 or lgreenman@thearcctn.org. ■

national Center for Excellence in Developmental Disabilities Research, Education and Service (UCEDD). But the advances developed at the Center would be unsuccessful if it were not for community participation. Two important, and expanding, aspects of the Vanderbilt Kennedy Center dependent on community involvement are research studies and the Community Advisory Council.

StudyFinder Provides a Map

Our health and the quality of our lives and of our family members' lives are better because of the discoveries of medicine, psychology, education, and countless other fields. Most of us never have a chance to make scientific discoveries ourselves. But we can be a partner in discovery—by taking part in research.

The Center welcomes the participation of children and adults, with and without disabilities. In some studies, free services are provided that may directly benefit the participant. In other studies, participants will have the satisfaction of contributing to knowledge. Some studies pay volunteers a modest amount for their time.

Families and service providers now have "StudyFinder," a Web site to easily find research studies that may offer intervention or in other ways advance knowledge of development and developmental disabilities. StudyFinder is for anyone interested in taking part in research.

Users can search by topic [for example, autism, developmental disability] to receive a "Report" of research projects that are a possible fit. The Report provides a brief description and contact information. Your query is confidential.

You can find StudyFinder on the Center's Web site at <http://kc.vanderbilt.edu/studyfinder>. For specific information, e-mail the individual listed for each project

described. For general information, contact Lynnette Henderson, (615) 936-0448, or lynnette.henderson@vanderbilt.edu.

Connecting with the Community A Community Advisory Council (CAC) was formed in 2005 to advise the Vanderbilt Kennedy Center leadership. It's a full partner in planning, implementing, and evaluating activities. This Council is chaired by Doria Panvini, parent of an adult son with intellectual disabilities. Panvini is well-respected in Tennessee as an effective advocate for individuals with disabilities and their families. Although members are still being recruited, 13 already have been appointed.

The Council has a five-part mission: (1) to consult with the director of the University Center for Excellence in Developmental Disabilities regarding the progress of the Center in meeting projected goals and to make recommendations, (2) to develop an overall understanding of the Vanderbilt Kennedy Center and its work, (3) to review, to advise, and to make recommendations regarding the Vanderbilt Kennedy Center programs, (4) to collaborate with Vanderbilt Kennedy Center researchers on applied and clinical research, and (5) to collaborate on development of programs with family and community focus.

"The Community Advisory Council will bring the perspective of families and people with disabilities to the research, training and outreach programs at the Kennedy Center," said Panvini. "Through their community involvement with the Community Advisory Council, they are able to identify the areas that are of concern to families and will help to develop a stronger collaborative relationship between the community and the Kennedy Center."

Interests and concerns can be communicated to Panvini by emailing vkac@vanderbilt.edu. ■



There are many acronyms and terms associated with the DMRS. In each issue of *Personally Speaking* we'll serve up a small portion of Division alphabet soup.

- AAMR - American Association on Mental Retardation
- ISC - Individual Support Coordinator
- CLA - Community Living Arrangement
- LOC - Level of Care

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Personally Speaking Listens!

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Got ideas or opinions? Send them our way!

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